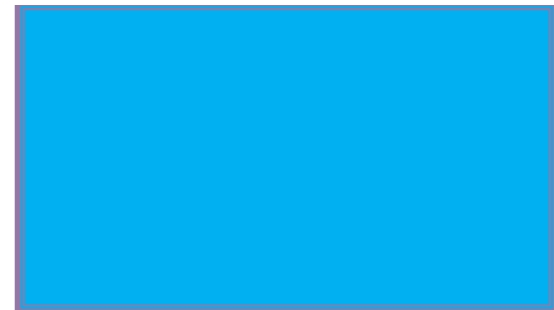




WHO Collaborating Center
for Maternal and Child Health
Trieste Italy



Quality of Maternal and Newborn Health Care
Translating research into policy initiatives
in the WHO European Region

Family Integrated Care in NICU

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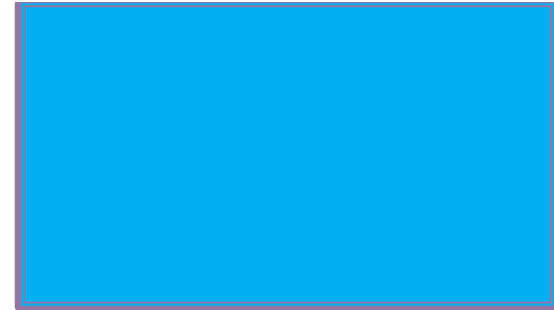
Mariana Amorim, Susana Silva

EPIUnit - Instituto de Saúde Pública, Universidade do Porto; Departamento de Ciências da Saúde Pública e Forenses e Educação Médica, Faculdade de Medicina, Universidade do Porto; Laboratório para a Investigação Integrativa e Translacional em Saúde Populacional (ITR), Portugal

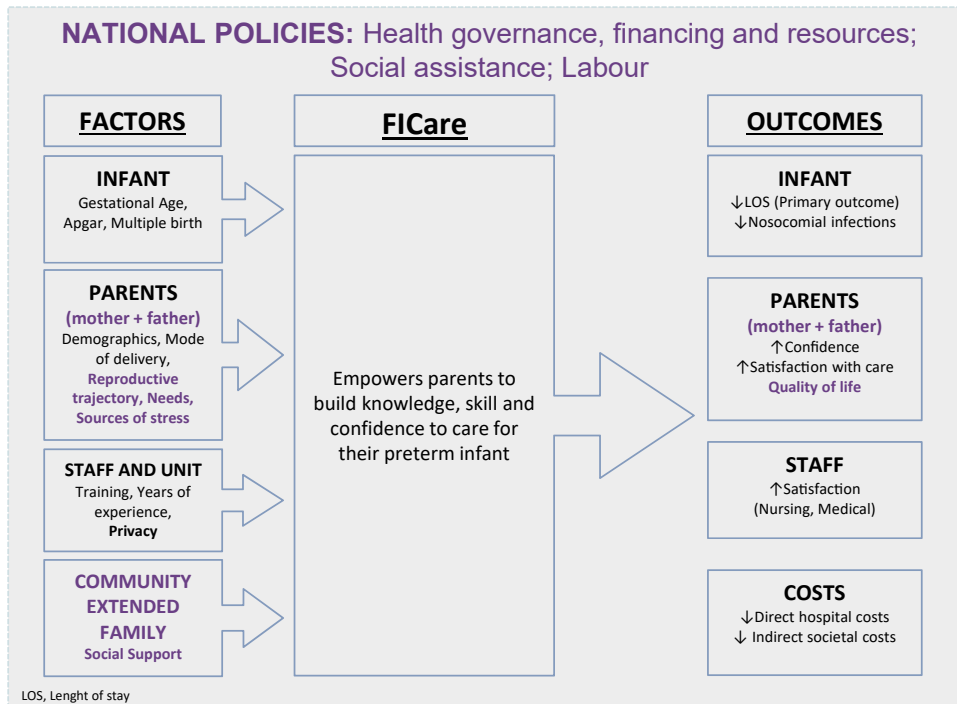


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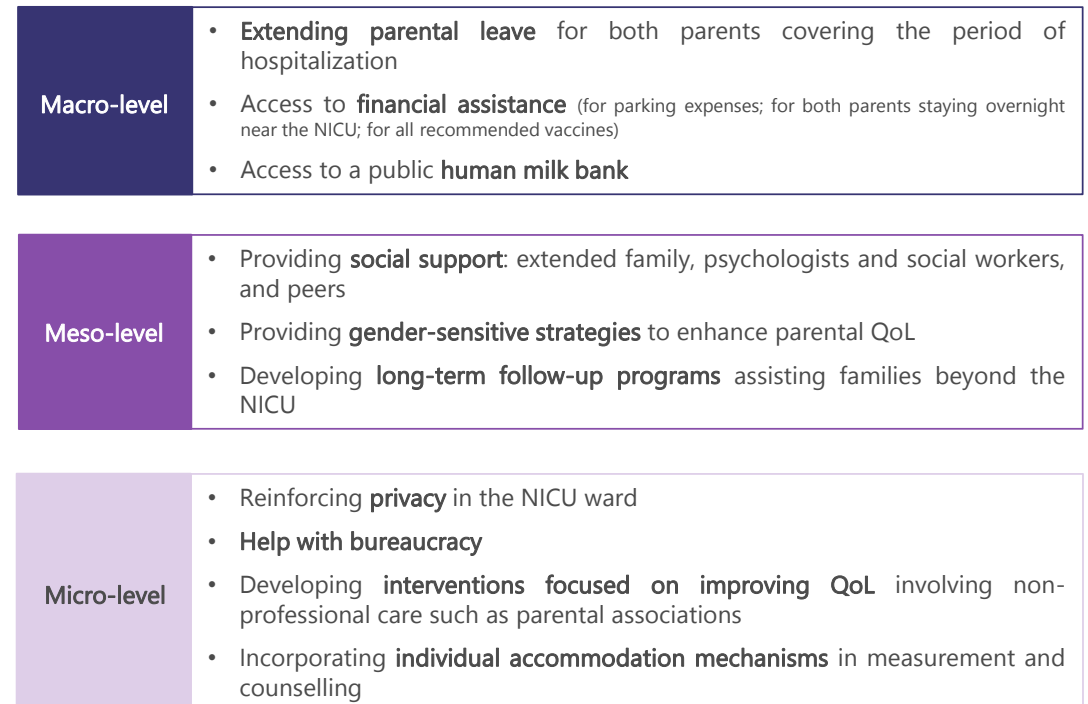
1. What?



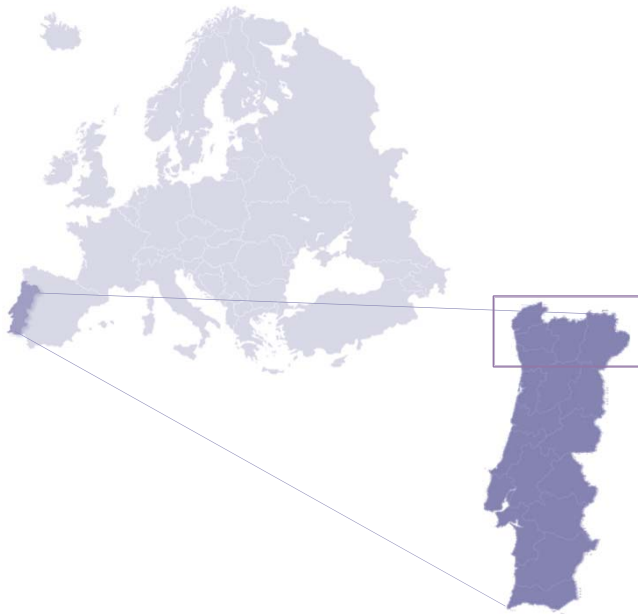
Evidence about Family Integrated Care (FICare): What is missing?



To translate evidence on parental needs and QoL into national FICare guidelines is needed:



2. When & Where?



July 2013 - June 2014

During hospitalisation
15 to 22 days after childbirth

7 NICUs of the Northern Health Region of Portugal



- Complex socio-technical environments: unknown smells and lights, noisy life support/monitoring equipment, lack of privacy, constant surveillance.
- Difficulties in establishing parental roles, physical separation from the child, structured and controlled opportunities for interaction, limited involvement in infant's care, and fear/uncertainty about infant's survival and health/development.

November 2013 - November 2014

After discharge
≈4 months after childbirth

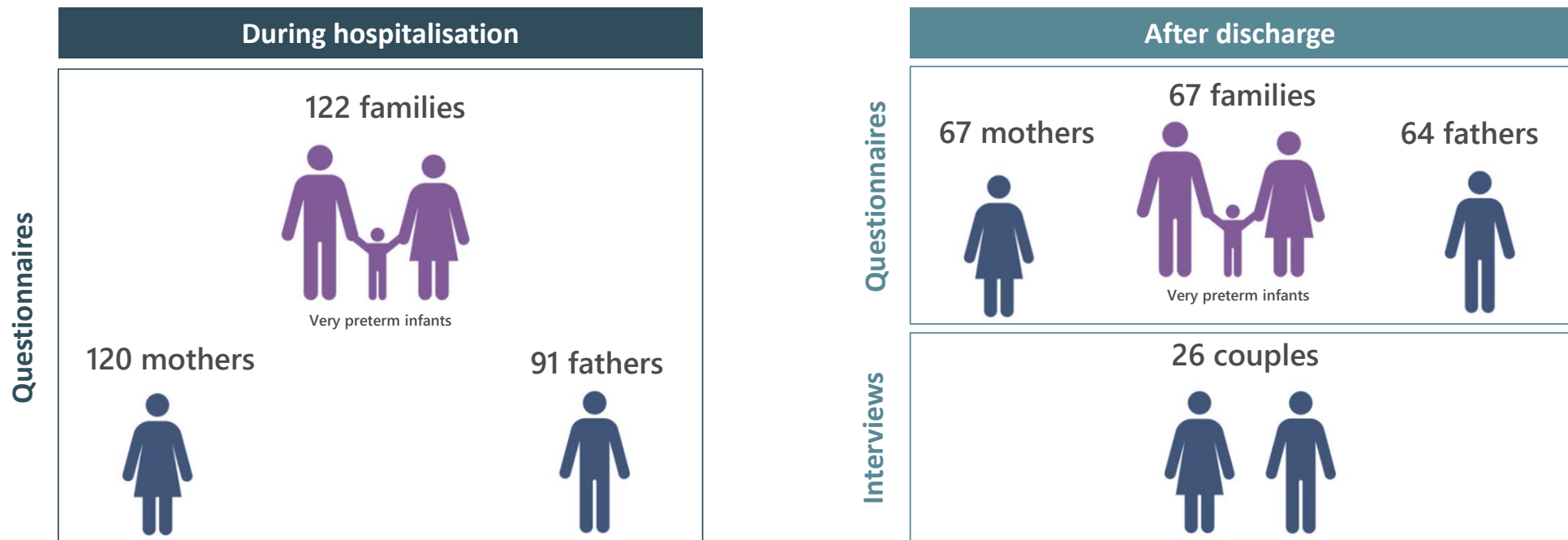
Portuguese Law: 4 months of parental leave with full pay salary after a childbirth



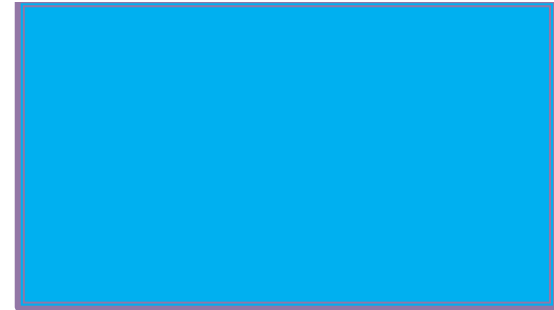
- At this time, portuguese law did not include the infant's hospitalization period in the parental leave.
- During hospitalization only one parent could ask for a subsidy corresponding to 65% of the salary.

3. Who?

Observational and longitudinal mixed methods study: key actors/stakeholders



4. How?



Methods of involvement

Questionnaires

- Sociodemographic characteristics
- Gynaecological and obstetric history
- NICU Family Needs
- Parental Stress in NICU
- Perceived Social Support
- Infant's length of NICU stay and diagnosis of health problems
- Parental QoL
- Anxiety and depressive symptoms
- Parenting stress

Semi-structured interviews

- Dealing with uncertainty and doubts
- Decisions concerning parental care, treatment options and information sources
- Understandings of medical facts, of technologies and of prognosis
- Views of life and living with handicaps
- Information and communication needs

Clinical Records

- Pregnancy, birth and neonatal characteristics

Consensual guidelines on FICare based on empirically-based recommendations responsive to parents' needs

Processes, activities and tools enacted:

(capital letters = most useful)

- Open dialogue about research results through **WORKSHOPS**
- **HOSPITAL MEETINGS** with the NICU's staff
- Publications in diverse scientific areas
- Media coverage

Directed to and involving **HETEROGENEOUS STAKEHOLDERS:**

- Key actors: neonatologists, nurses, parents and extended family
- External stakeholders: Policy makers

5. Why?



Policy Initiative: Implementation of FICare in NICU

Success factors	Conceptual	<ul style="list-style-type: none">• Challenge available models of care• Add parental QoL, stress and anxiety beyond infant-related outcomes
	Methodological	<ul style="list-style-type: none">• Combine quantitative and qualitative methods: a comprehensive approach• Include both mothers and fathers of very preterm infants
	Practical	<ul style="list-style-type: none">• Proposal of integrated policies• Help to design parents-friendly medical practices
	Science & Society	<ul style="list-style-type: none">• Broad media coverage (call for changing the regulation of parental leave was highlighted)• Engaging the community

Constrains	Social and political issues	<ul style="list-style-type: none">• Insufficient financial assistance• Non-flexible work schedules
	Organizational barriers	<ul style="list-style-type: none">• Lack of communication and negotiation skills• Time, human and material resources• Lack of guidelines including the parental perspectives and needs
	Family dynamics	<ul style="list-style-type: none">• Lack of social support• Financial constraints• Work commitments• Single parenthood• Dependent individuals demanding care

Lesson learned: Guidelines on FICare need to be aligned with parents' views and needs in order to be effective



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